Quality of Nursing Care from the Perspective of Hospitalized Children with Cancer

Kathleen Riestenberg, Baccalaureate Nursing Student

Dr. Nancy Ryan-Wenger, PhD, RN, Advisor

The Ohio State University

College of Nursing

Abstract

Purpose: To determine characteristics of nurses and nursing processes that matter most to hospitalized children with oncology conditions. **Background**: Over three million children in the United States are hospitalized and over 8,500 children ages birth to 15 years are diagnosed with cancer annually. Nursing care is rarely evaluated by the children themselves. The importance of linking pediatric patients' hospitalization experiences, in relation to quality nursing care, and health related outcomes is under acknowledged. An especially vulnerable population of hospitalized children is oncology patients. They have a chronic disease requiring frequent and lengthy hospitalizations; therefore, their perceptions and needs are different. Previous studies has shown that children expect the nurse to be "nice", wear colorful clothing, have a sense of humor, and be there to listen to their concerns. However, there has been relatively little research done on the pediatric oncology patient population regarding their perspective of nursing care. **Subjects**: 39 children ages 6-21 years hospitalized for cancer treatment at Nationwide Children's Hospital. **Methods**: Children completed a PedsQL-PF Form, Revised Children's Anxiety and Depression Scale (RCADS), hospitalization experience interview, and human figure drawing. The PedsQL Present Functioning Scale measures anxiety, sadness, anger, worry, fatigue, and pain. The RCADS form measures general level of depression and anxiety. The interview assesses the children's opinions on what nurses have done that is "pretty good" and what nurses have done that needs improvement. The human figure drawing is a projective technique that assesses children's thoughts, emotions, and feelings. **Results**: The two most common "liked" nursing qualities were "nice/friendly", and "gives me medication". The two most common "disliked" nursing qualities were

“uncomfortable procedures” and “wakes me up”. Females and early adolescents responded more frequently. **Conclusions**: Understanding this vulnerable population of children’s hospitalization experience and expectations will help nurses provide quality care in response to their concerns.

Keywords: quality of care, pediatric oncology, nursing care

Introduction

Over 3 million children in the United States are hospitalized yearly, according to 2006 statistics from Centers for Disease Control and Prevention (CDC, 2010). Evaluation of children's care is typically done by parents through mailed patient satisfaction surveys (Pelander & Leino-Kilpi, 2004). Nursing care is rarely evaluated by the children themselves. The importance of linking pediatric patients' hospitalization experiences, in relation to quality nursing care, and health related outcomes is under-acknowledged, as children are seldom permitted to express their concerns and expectations about their nursing care. It is necessary for children to convey their hospitalization experience and expectations so that nurses can respond to their concerns while they are hospitalized (Coyne, 2006). An especially vulnerable population of hospitalized children is children with oncology conditions. Compared to the average medical/surgical patient, many children with cancer have a chronic disease, and sometimes have acute episodes, and frequent and lengthy hospitalizations. Therefore, their perceptions of care and their needs may be different (Berríos-Rivera, et. al 2008).

The purpose of this study was to describe the hospitalization experience of children with cancer. The research questions were: (a) what are the nursing care processes that matter most to children with cancer during their hospitalization experience? (b) how do these nursing care processes differ according to children's age group, sex, and previous hospitalization experience? (c) what is the psychophysiological context (i.e., quality of life, anxiety, depression, emotions) in which children responded?

Review of Literature

Annually in the United States, over 27,000 children ages birth to17 years are hospitalized for cancer (CDC, 2010), most commonly leukemias, lymphomas, central nervous system, and bone, soft tissue, or renal tumors (Ross, & Olshan, 2004). According to the National Cancer Institute (NCI, 2009), cancer is the leading cause of death for children ages birth to 15 years, and in 2008, the NCI expected 10,730 newly diagnosed cases of pediatric cancer in children ages birth to14 years. Protocols and outcomes of pediatric cancer treatment are widely researched, but there is no research that has focused on the quality.

Children's Hospitalization Experiences

Literature on the experiences and expectations of children hospitalized for other medical reasons can be informative. In a qualitative analysis, Coyne (2006) found that children (n=11), ages 7 to 14 years, experience stress from separation from family and friends, being in an unfamiliar environment, receiving painful treatments, and losing self-determination (loss of control). It was also concluded in that study that good communication between health care providers and children lead to better understanding of their illness and treatment plans, which ultimately caused less stress for the children during hospitalization. This finding emphasizes the importance of the relationship between nurses and the children, as the quality of the care nurses give can positively affect health related outcomes in their patients. Pelander and Leino-Kilpi (2004) conducted a qualitative study on expectations about nursing care among 20 preschool and 20 school-age children who have a chronic disease or had been hospitalized for short period of time. They found that these children expected the nurse to be "nice," to wear

colorful clothing, have a sense of humor, provide entertainment, give information related to their care, and be there to listen to their concerns. The authors also pointed out the need for a tool to assess the quality of nursing care from children's perspective, based on the children's expectations.

The literature review revealed one phenomenological study that focused on the hospitalization experience of children with cancer, but there were quite a few limitations associated with the sample (Berríos-Rivera, et. al 2008). The sample included 18 participants, including 7 patients and their mothers, 2 oncology nurses, and 2 oncologists. The type of cancer was limited to acute lymphocytic leukemia and the findings of the study were based mostly on the mothers' point of view, with agreements or disagreements from their children noted. Results showed that children found the hospital to be a safe haven due to their rapport with the oncology treatment team, experienced difficulties with pain and side effects from their treatment, took control of their situation by educating themselves about the disease, and thrived during this adversity with a positive attitude. There is a need for more research to be done regarding the cancer hospitalization experience specifically from the children's perspective. No quantitative studies concerning hospitalized children's experiences were found.

Symptom Distress Experienced by Pediatric Oncology Patients

Not only does the overall hospital experience play a role in children's perspective of quality nursing care, but the symptoms and side effects of cancer treatment also contribute to their expectations and evaluation of the health care they receive. Therefore, it is important to research the types of symptoms pediatric cancer patients experience and the effectiveness of nursing interventions for them. Rheingans (2008) described the

results of a national descriptive survey of 509 pediatric oncology nurses regarding their level of distress related to their patient's symptoms, on a scale of 0 to 4, and the effectiveness of nursing interventions, on a scale of 0 to 4. According to the literature, fatigue and mouth sores (mucositis) were among the most distressing symptoms experienced by patients, but were reported by the nurses as occurring less often than other symptoms, such as pain, nausea, vomiting, hair loss, and worry. Nurses were most distressed by the pain experienced by their patients, and children reported that the most effective nursing interventions were for pain. Fatigue was perceived by 86% of the nurses to be among the least distressing symptom (mean score=2.7, SD=1.6), and was least effectively managed with nursing interventions (mean=2.1, SD=0.8). These findings show that children's and nurses' perspectives are very different, which emphasizes the need for an evaluation of nursing care from the child's perspective.

Corey, Hasse, Azzouz, and Monahan (2008) evaluated the social support provided by family, friends, and the health care team as it related to the presence or absence of symptoms of depressed mood, pain, fatigue, and insomnia from the perspectives of adolescents and young adults with cancer (n=199). This secondary analysis of the Adolescent Resilience Model found that with greater perceived support from the health care provider the less insomnia patients experienced (Odds Ratio=0.38, p=0.0275). More perceived support from family and friends was found to be related to less depression and anxiety in patients ($r = -0.197$ to -0.249, $p < 0.05$), with females more positively affected by the support than males. This study, however, cannot predict causal relationships since it is a cross-sectional design, and not prospective. The sample consisted of participants

across the cancer "continuum" ranging from being newly diagnosed to having many years of treatment.

In a longitudinal qualitative interpretive design, Woodgate, Degner, and Yanofsky (2003) described the childhood cancer symptom course from the perspectives of 39 children, ages 4 ½ to 18 years, and their families. Children became troubled when asked to rate a single symptom on a self-report scale as they could not easily decide which symptom was most distressful to them and did not feel the scale truly expressed how the symptom made them feel. The authors also found that children were more inclined to discuss their symptom experience when they had meanings attached to them, for example "I have a sick stomach", rather than being associated with physiological or psychological states, i.e. nausea. Health care providers were not always aware of how the children were feeling, which therefore affected the possibility of providing complete symptom relief. The involvement of family is essential, according to this qualitative study, as they can play a part in relieving the symptoms that pediatric oncology patients experience. One of the most important findings was the need to acknowledge that cancer symptoms involve multi-dimensional factors including environmental, personal, and treatment-related issues and are not just single physiological or psychological states. The authors encourage health care providers to seek out what the symptoms mean to children and their families to better understand the affect symptoms have on the children. Although this study involved mostly white participants and included little diversity, further research on this topic would yield very valuable information.

Quality of Life in Pediatric Oncology Patients

Two studies examined quality of life after children received bone marrow transplants (BMT). The first study focused specifically on somatic distress and mood disturbance (Phipps, Dunavant, Garvie, Lensing, & Rai, 2002). Children ages less than one year to 20 years who participated in this study (n=153) were assessed in a longitudinal, prospective design, starting with the time of admission, followed by weekly assessments up to six weeks after the BMT, then monthly up to six months post BMT. Somatic distress symptoms included daily functioning activity, nausea/vomiting, mucositis, appetite loss, fatigue/malaise. The mood disturbance indicators were feeling sad/subdued, fearful/anxious, angry/irritable, and sleep disturbances. Results indicate that on admission, children have high levels of somatic distress, experience great mood disturbance, and have low levels of activity. This experience for the children increases dramatically until one week after the transplant. The rise in symptom distress starts to decline back to admission symptom levels by week 4 and 5 post BMT, continuing to reach presumed basal levels by months 4 to 6. This study used both parent and child report, which was shown to be surprisingly similar, ultimately validating the findings. Although the children experienced aggressive supportive care, indicated by anti-emetic medications, narcotic analgesics, and a high level of psychosocial support, it seems that it had little to no effect on the amount of distress the children suffered. Although this study used a sample generated from a single institution, its findings suggest the need for a more aggressive style of supportive care, focusing on interventions that treat the acute phase of the transplant where the most distress is experienced. This study can provide a foundation for understanding the experiences of children during the intense treatment option of

BMT, which ultimately affects the way they view quality nursing care. The fact that the supportive care given to these children had low levels of effectiveness on relieving symptom distress requires further investigation.

Phipps, Dunavant, Lensing, & Rai (2002) conducted a secondary analysis of the study above, focusing on medical and demographic variables within the sample of 153 children and their parents as predictors of health-related quality of life, measured by somatic distress, mood disturbance, and activity. These variables included transplant type, diagnostic group, gender, age, and socioeconomic status. Results indicated that symptom distress was highest among those receiving unrelated donor transplants, followed by those receiving matched-sibling transplants, and lastly, autologous transplant recipients ($F=17.3$, $p<0.0001$). An increase in age was associated with higher levels of distress ($F=20.9$, $p<0.0001$), while there were no significant differences in quality of life by gender. Lastly, the lower socioeconomic status indicates mood disturbance and less activity along the BMT timeline. This indicates that the focus of supportive nursing care may need to be different according to medical and demographic characteristics of the patients.

While parents' perspectives of their child's well-being are important, patient self-report of health-related quality of life, especially involving the effects of cancer treatment, may be more reliable in determining the best quality of nursing care. The need to make nurses aware of the differences in 149 parents' and perspectives of the children's quality of life is shown in the Matziou et al., (2008) study, which evaluated the level of agreement between the two reports and the factors that affected that relationship. After evaluating both patient and parental responses concerning physical, emotional, social,

and school functioning, they found that children tended to report better quality of life than did their parents. While physical, social, and school reports had high correlations ($r = 0.58$ to 0.84, $p<0.05$) between the two groups, parents reported the child having lower emotional functioning ($r = 0.52$, $p<0.05$). The researchers think that parents' own worries, fears, and anxieties about their child's diagnosis and treatment are reflected in their report of their children's health-related quality of life. This study compared patients who were newly diagnosed and currently on treatment regimens with those who completed their treatment course, but were still coming in for check-ups. This factor affected the correlation between the reports of quality of life. Children who were in the on-treatment group tended to report better quality of life than their parents ($r = 0.65$, $p<0.05$), while the off-treatment group had a much higher correlation between the two sets of reports ($r = 0.76$, $p<0.05$). Although the sample represents only one oncology ward and according to the authors, the size was small, this study suggests a need for children's self-reports on their own quality of life. Nurses should assess the children's health-related quality of life and incorporated this information into their nursing care. Perhaps more clinically relevant would be an assessment of the children's quality of life at specific points in time, such as during a hospital stay.

Through this literature review it is evident that there is a need for more research on pediatric oncology patients' experiences in the hospital and their expectations for quality nursing care. The purpose of this research project is to determine the characteristics of nurses and nursing care processes that matter most to hospitalized children with oncology conditions.

Methods and Design

This was a cross-sectional descriptive study in which information was obtained from children about their positive and negative hospitalization experiences regarding interactions with nurses, and the psychophysiological context in which they responded to the interviews. This research is a secondary analysis of a larger study of 502 hospitalized children called "Quality of Pediatric Nursing Care from the Children's Perspective" (Principal Investigator: Nancy Ryan-Wenger. The children with oncology conditions were selected for this study.

Sample

The target population was children ages 6 to 21 years who are hospitalized for oncology diagnosis and treatment. The sample was obtained from a large, Midwest, free-standing children's hospital. Inclusion criteria were chronological age of 6 to 21 years, developmental age of at least 6 years, English-speaking, admission to the hospital for more than 23 hours, and an oncology diagnosis.

Procedure

After a complete explanation of the study by a research assistant, parental consent and HIPPA approval were obtained, as well as the child's assent (if age 9 to 17) or consent (if age 18 to 21). Parents completed a demographic form for the child, as well as other questionnaires that are not included in this secondary analysis. The children completed a 6-item quality of life scale, and anxiety and depression scale, a semi-structured interview on their hospital experience, and a human figure drawing. The total amount of time required from each child ranged from approximately 20 to 45 minutes. All children received a gift certificate worth $5 to the hospital's gift shop.

Instruments

A demographic data form included age, sex, ethnicity, and number of previous hospitalizations. Clinical data obtained from the medical records included admission and discharge dates and diagnoses.

Quality of life was measured by the PedsQL Present Functioning Scale (PedsQL-PF) (Sherman, Eisen, Burwinkle, & Varni, 2006), a tool designed as an "ecological momentary assessment" of children's and adolescents' "present, at-the-moment functioning" (p.1). This 6-item scale requires children to evaluate their current levels of feeling anxious, sad, angry, worried, fatigued, and pain. Originally, items were scored on a visual analog scale on a 0 to 100 mm line, with circular smile, straight and frowning "faces" evenly spaced below the line as a visual guide. Internal consistency reliability of the PedsQL-PF was 0.72 to 0.84, and construct validity was supported by moderate to large correlations between Emotional Distress scores and Pain scores. Scoring the VAS required labor-intensive measurement of the length of each line for each item. In collaboration with the developer (Varni), we changed the scale to 1=not [i.e., anxious], 2=just a little, 3=more than a little, 4=very, and 5=extremely, and retained the circular faces below the response options. Similar to the original version, better quality of life is indicated by lower total scores.

Anxiety and depression were measured by the Revised Children's Depression and Anxiety Scale (RCADS) (Chorpita, Moffitt, & Gray, 2005). There are 47 items with 4-point ordinal response options, scoring 0 to 3 for *never, sometimes, often,* or *always*. Six subscales measure separation anxiety, generalized anxiety, panic, social phobia, obsessive compulsive disorder, and depression. Total scores range from 0 to 111 and

Cronbach alphas in the reliability sample ranged from 0.71 to 0.85. Construct validity was supported by relatively high positive correlations with the Children's Depression Inventor (r = 0.65 to 0.80) and Spence Children's Anxiety Scale (r = 0.65 to 0.82).

Children also completed a Human Figure Drawing (HFD), which is a projective measure of the children's thoughts, emotions, and feelings. Children were given a pencil and asked to draw a picture of a person – any person – on a blank 8 ½ x 11 piece of white paper. These drawings were examined for the presence or absence of emotional indicators (EI), which are "clinical signs that reflect underlying attitudes and characteristics of children at the time they make the HFD's" (Koppitz, 1984, p.23). EI's consist of unusual or unexpected characteristics (i.e., shading of the face, large hands, genitals) and omissions of expected characteristics (i.e., no eyes, no hands, no neck). According to Koppitz (1984), these emotional indicators occur in less than 16% of HFD's and significantly more often in HFD's of children with emotional problems compared with children who are considered well-adjusted. The list of EI's that were examined in this study were derived from work published by Koppitz in 1968 and 1984.

Children's perceptions of their hospitalization and nursing care were measured by their responses to an investigator-developed Children's Semi-Structured Interview. Content validity was supported by deriving questions from theory, clinical experience, and a literature review. This study summarizes children's responses to two questions: "What do nurses do that you like?" and "What do nurses do that you don't like?"

Results

Sample

The sample consisted of 39 hospitalized children ages 6 to 21 (mean = 12.69, SD = 4.7). 64.1% (n=25) of the sample were male and 35.9% (n=14) were female. 32% of the sample was white, 7% was black, and 0% was Hispanic or had a Latino background. These children had previous hospitalizations ranging from 0 to over 200 times with their length of stay at the time of the interview ranging from 1 day to 118 days. Most of the children were admitted to the hematology/oncology unit, J5, (n = 30), while others had their experience on the cardiology, neurology, surgery, infectious disease, or respiratory units (n total = 9). All of the children had a diagnosis of cancer (Table 1). The three most common forms were Acute Lymphoblastic Leukemia (ALL) (n=11), osteosarcoma (n=5), and Acute Myeloid Leukemia (AML) (n=4). Table 1 shows all of the diagnoses from the sample.

Nursing Care Processes that Matter Most to Children with Cancer

To analyze what nursing care processes matter most to hospitalized children with cancer during their hospitalization experience, categories were created from the children's interview data by sorting the responses into 18 "like" categories and 14 "dislike" categories. Frequencies and percentages were then calculated and compared (Tables 2 and 3). The four most common "liked" nursing characteristics/processes were being nice/friendly (n=18, 12.9%), gives me medication (n=16, 11.4%), checks on me often (n=12, 8.6%), and plays with me (n=12, 8.6%). Each child in the sample population responded with one to ten things that they liked about the nurses. The four most common "disliked" nursing characteristics/processes were uncomfortable procedures (n=10,

19.6%), wakes me up (n=9, 17.6%), not being responsive to my needs (n=7, 13.7%), and other/miscellaneous things (n=7, 13.7%).

Demographic Differences

To analyze how the nursing care characteristics/processes differed according the children's age group, sex, and previous hospitalization experience, chi square analysis and independent t-tests were conducted for each "like" and "dislike" category (Tables 4, 5, 6, and 7). Significant differences in gender and age group were noted. More females (14.3%) reported things they liked about the hospital environment, while none of the males answered within this category (χ^2=3.764, p=0.052). Within the "makes me comfortable" category, 50% of females responded with an answer compared to 16% of males (χ^2=5.123, p=0.024). Lastly, 50% of females, but only 20% of males liked that nurses checked on them often (χ^2=3.792, p=0.052).

There were three significant age group differences among the "like" categories. Among the children who liked nice and friendly nurses, 87.5% of early adolescents (ages 11-14) were more likely to say this compared to other age groups (χ^2=10.23, p=0.037). 80% of young schoolagers were more likely to say that they liked when nurses played with them (χ^2=11.185, p=0.025). Lastly, children who enjoyed being checked on by nurses were most often early adolescents (62.5%, χ^2=10.012, p=0.04). There was only one significant difference among the "dislike" categories when comparing age group and gender. More females (35.7%) than males (8%) answered that they do not like it when nurses are not responsive to their needs (χ^2=4.680, p=0.031).

The number of previous hospitalizations for these children ranged from 0 to over 100. For six children, this was their first hospitalization; the second hospitalization for

seven children; twelve children had between 2 and 10 hospitalizations; and thirteen had 20 or more previous hospitalizations. Missing data accounted for the remaining child. The relationship between number of hospitalizations and the "like" and "dislike" categories was measured by an Eta correlation. Results show a positive relationship between previous hospitalizations and nursing characteristics, i.e. the more previous hospitalizations, the more that children found each of these positive characteristics to be important to them. The Eta correlations ranged from 0.549 to 0.824 for the "like" categories and ranged from 0.456 to 0.810 for the "dislike" categories.

Psychophysiological Context

It is important to understand the psychophysiological context in which the children responded to their interviews. The PedsQL-PF instrument had a range of scores form 0 to 11 of a positive 24 points, with a mean of 3.15 and a standard deviation of 2.80. With this instrument, a low score means higher quality of life. Two children had scores of 11. Subscales of the RCADS questionnaire included separation anxiety, generalized anxiety, panic, social phobia, obsessive compulsive, and depression. A T-score of 60 or higher is clinically significant and merits further assessment. The average scores were within normal limits for all 6 subscales (Table9). T-scores were clinically significant for four children on the separation anxiety scale (T=60, 63, 89, 90); three children on the generalized anxiety scale (T=62, 65, 66); four children on the panic scale (T=61, 61, 64, 64); one child on the social phobia scale (T=78); two children on the obsessive compulsive scale (T=65, 65); and five children had clinically high depression scores (T=60, 61, 63, 71, 86).

Only 29 or 39 children completed human figure drawings due to refusals (n=2), tiredness (n=1), and visitors in the room (n=1). HFDs were added to the protocol for the adolescent age group after 6 of these adolescents had already participated. The total number of EIs on the drawings ranged from 1 to 7 of a possible 30 EIs (median=3, mode=3). Two or more emotional indicators are present in only about 10% of drawings by children in the community (Koppitz, 1968, 1984). In this sample of children hospitalized with cancer, 82.8% of the children demonstrated 2 or more EIs in their human figure drawings. As expected, the three measures of psychophysiological context were interrelated. The PedsQL-PF scores were significantly correlated with for of the six RCADS subscales (r=0.36 to 0.47) (not including the separation anxiety and panic subscales), and the frequency of the EIs correlated positively with PedsQL-PF scores (Eta=0.39), and with all of the RCADS subscales (Eta=0.57 to 0.82).

Discussion

Nursing Care Processes that Matter Most to Children with Cancer

Overall, children hospitalized with a cancer diagnosis and treatment are not much different than the average hospitalized child with respect to what they like about their nurses and nursing care, and what they dislike. For example, similar to the Pelander and Leino-Kilpi (2004) study in which hospitalized children most frequently expected their nurse to be nice and kind, responses in the “nice/friendly” category were most frequent (n=18, 12.9%). Other similar findings in both studies are that children like nurses to provide entertainment by “playing with me” (n=12, 8.6%) and they felt safe by having nurses “check on me often” (n=12, 8.6%). The second most common “liked” nursing characteristic for this sample was “gives me medication” (n=16, 11.4%). This is

particularly important to the oncology population as symptoms these children experience are in need of medication therapy. Rheingans (2008) found that pediatric oncology patients experience distressing somatic symptoms including fatigue, pain, poor appetite, nausea/vomiting, hair loss, and mouth sores. This study's results showed that nursing interventions, mostly including pharmacologic management, were most effective for pain. In looking at the types of interventions used for the somatic symptoms, pharmacologic management was the most common treatment mentioned. Therefore, these children expect and "like" when nurses bring them medications to treat distressing symptoms common to the oncology population.

In a qualitative study, Coyne (2006) examined reasons why hospitalized children experience stress. Her results are similar to the outcomes found in this research. While Coyne found that stressful experiences include receiving painful treatments, being in an unfamiliar environment, and losing self-determination, for children in this study uncomfortable procedures (n=10, 19.6%) was the most common "dislike" nursing characteristic reported compared to receiving painful treatments. Being in an unfamiliar environment and losing self-determination were further divided into sub-categories, including bright lights at night and losing control over sleeping and waking times. This can be compared to the second most common "dislike" which was "wakes me up" (n=9, 17.6%). The third most common "dislike" from this study is "not being responsive to my needs" (n=7, 13.7%), which can be linked to the significance of good communication. Coyne also found that good communication between the health care provider and children ultimately leads to less stress for the patient, including a nursing characteristic that is important in providing quality care.

Demographic Differences

With respect to the differences of nursing characteristics between males and females, more females identified “makes me comfortable” and “checks on me often” were important to them. Corey, et al. (2008) also noted that females are more positively affected by social support, which is reflected in the fact that more females liked when nurses provided comforting care and checked up on them, and expressed concerns when nurses did not respond to their needs.

The Corey, et al. (2008) study found that, particularly in adolescents, social support from health care providers has a positive influence on relieving stress. In this study, we noted developmentally appropriate differences in responses among age groups. For example, more early adolescents were likely to respond that they “liked” nurses who were “nice/friendly” than any other age group. Also, more early adolescents responded in the “checks on me often” category because the children need the support by the health care provider to lessen the stress from the hospital stay. Young school-agers were more inclined to respond that they liked when nurses played with them compared to the other age groups, which is developmentally appropriate.

Previous hospitalization experiences ranged from none to over 100, and there was a positive relationship between the number of previous hospitalizations and nursing characteristics that matter most to children (Eta statistics ranged from 0.549 to 0.824), suggesting that children’s expectations, likes and dislikes about their nursing care become more important to them.

Psychophysiological Context

The context in which these children participated in the study included their quality of life and psychological status. Despite the pain and stress of cancer treatment and lengthy hospitalizations, most of these children did not demonstrate high levels of anxiety or depression. Their present functioning quality of life scores indicated relatively positive quality of life. Clinically, it is important to recognize when children need further assessment and intervention. For example, a 17 year old male with a brain tumor interviewed on the 9th day of his 10-day stay, had clinically high scores in all RCADS subscales. On the quality of life scale, he indicated that he was more than a little worried, and his HFD included 6 emotional indicators. An eight year old boy with newly diagnosed ALL and no previous hospitalizations reported on his 8th day of his 9-day stay that he was extremely sad and angry. Also, his score on the panic subscale of the RCADS was above the clinical range, but his HFD included only 2 emotional indicators. His depression and anxiety scores were within normal limits. An 18 year old girl with Ewing's sarcoma who had never been hospitalized before reported on the last day of her 4-day stay that she was extremely worried on the quality of life scale, which was consistent with her clinically significant scores on all RCADS scales except obsessive compulsive.

The standardized RCADS is a lengthy assessment tool that is useful for research, but not feasibly for daily clinical use. However, the 6-tem present functioning quality of life tool (PedsQL-PF) is quick, easy, and correlates well with the RCADS, and could be incorporated into nurses' daily assessments of their patients. From the hospitalized patients' perspectives, this study revealed specific nurse characteristics and nursing

processes that matter most to them. Most of the characteristics and processes that they like are simple to maintain, and what they dislike are simple to alter. All hospitalized children should have the opportunity to comment on the quality of their care, at least daily, or more often. Perhaps this assessment could be the "6th vital sign" that nurses assess and respond to on a regular basis. If so, it seems that everyone, including the children, their parents, and their nurses would benefit.

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Table 1. Frequencies and Percentages of Cancer Diagnoses

Diagnosis	*Frequency*	*Percent of Total (n=39)*
ALL	11	28.2
Osteosarcoma	5	12.8
AML	4	10.3
Burkitt's Lymphoma	3	7.7
Rhabdomyosarcoma	3	7.7
Brain tumor	2	5.1
Large Cell Lymphoma	2	5.1
Leukemia (not specified)	2	5.1
Ewing's Sarcoma	2	5.1
Osteomyelitis	1	2.6
Pilocytic Astrocytoma	1	2.6
Pseudotumor	1	2.6
Hepatic Carcinoma	1	2.6
Lymphoblastic Lymphoma	1	2.6

Table 2. Nursing Care Processes that Matter Most to Hospitalized Children with Cancer (n=39), "LIKES"							
Nursing Characteristic	*Frequency*	*Percent of Sample*	*Percent of Total Number of Responses (n=140)*	*Examples*	*Demographic Differences:*		
					Gender	*Age Group*	*Number of Previous Hospitalizations*
	n	***%***			χ^2 ***p***	χ^2 ***p***	***(Eta value)***
Nice, Friendly	18	46.0	12.9	"They come in my room happy and cheerful" "They are extremely sweet. They give me compliments and encouragement"	Girls=Boys **2.89 0.09**	Early Adolescents > all others **10.23 0.04**	0.612
Gives me medication	16	41.0	11.4	"Whenever I feel nauseous, they bring me medication to help me feel better" "When I'm hurting, the nurse gets the medications as soon as possible"	Girls=Boys **0.03 0.86**	Equal across all age groups **0.36 0.99**	0.624
Checks on me often	12	30.7	8.6	"They ask me if I need anything all the time" "They check on me often to make sure I'm ok"	Girls>Boys **3.79 0.05**	Early Adolescents > all others **10.01 0.04**	0.749
Plays with me	12	30.7	8.6	"Some of the nurses play board games with me" "They play games with	Girls=Boys	Younger Schoolage > all others	0.649

				me, entertain me"	**0.89 0.34**	**11.19 0.03**	
Makes me comfortable	11	28.2	7.9	"They always tell me the truth. They always tell me what they are going to do to me" "They tell me how my medications work"	Girls>Boys **5.12 0.02**	Equal across all age groups **5.17 0.27**	0.679
Responsive to my needs	11	28.2	7.9	"They get me what I want, when I need it" "They come quickly when I need them"	Girls=Boys **0.61 0.44**	Equal across all age groups **0.61 0.96**	0.600
Talks, listens to me	11	28.2	7.9	"They take good care of me by talking to me" "They stay here and talk to me, get to know me"	Girls=Boys **2.32 0.13**	Equal across all age groups **6.16 0.19**	0.780
Laughs and jokes with me	9	23.1	6.4	"She makes me smile. She is funny" "They are fun to be with"	Girls=Boys **0.03 0.86**	Equal across all age groups **7.03 0.13**	0.725
Give me things to do	8	20.5	5.7	"They put a Wii in my room" "They bring me board games"	Girls=Boys **0.01 0.92**	Equal across all age groups **2.51 0.64**	0.668
Other things, miscellaneous	8	20.5	5.7	"They act as go between from me to the doctors" "The nurses are very consistent and efficient"	Girls=Boys **0.01 0.92**	Equal across all age groups **2.36 0.67**	0.684

Helps me do things	7	17.9	5.0	"They walk around with me" "She let me push the syringe after she put the needle in me"	Girls=Boys **1.73 0.19**	Equal across all age groups **2.16 0.71**	0.824
Brings me food/drinks	5	12.8	3.6	"They offer to order me food when my mom isn't here" "She gave me ice cream"	Girls=Boys **0.63 0.43**	Equal across all age groups **4.55 0.34**	0.704
Cares about me	5	12.8	3.6	"They take the time to bond and find common interests with me" "They are very kind and caring"	Girls=Boys **1.45 0.23**	Equal across all age groups **3.44 0.49**	0.651
Takes care of me	4	10.3	2.9	"They take care of me" "They don't forget to do things, like flush my lines"	Girls=Boys **0.39 0.54**	Equal across all age groups **2.61 0.63**	0.549
Likes about the environment	2	5.1	1.4	"When they come in at night, they are quiet" "They keep everything clean"	Girls>Boys **3.76 0.05**	Equal across all age groups **3.03 0.55**	0.740
Gives me respect, privacy	1	2.6	0.7	"They treat me with respect"	Girls=Boys **1.83 0.18**	Equal across all age groups **3.98 0.41**	0.697

Table 3. Nursing Characteristics that Matter Most to Hospitalized Children with Cancer (n=39), "DISLIKES"

Nursing Characteristic	*Frequency*	*Percent of Sample*	*Percent of Total Number of Responses (n=51)*	*Examples*	*Demographic Differences:*		
					Gender	*Age Group*	*Number of Previous Hospitalizations*
	n	***%***			χ^2 ***p***	χ^2 ***p***	***(Eta value)***
Nothing	10	25.6	19.6		Girls=Boys **0.20 0.65**	Equal across all age groups **5.96 0.20**	0.654
Uncomfortable procedures	10	25.6	19.6	"They poke me with needles" "I don't like it when they come in to draw blood"	Girls=Boys **0.10 0.75**	Equal across all age groups **4.65 0.33**	0.810
Wakes me up	9	23.1	17.6	"The night nurses sometimes turn the lights all the way up, wake me up" "They wake me up to ask me to take my pill"	Girls=Boys **0.37 0.54**	Equal across all age groups **4.36 0.36**	0.725
Not responsive to my needs	7	17.9	13.7	"Sometimes they forget to bring the stuff I asked for, such as a spoon" "Sometimes they forget about things, one time I asked them to bring me a board game, they never	Girls>Boys	Equal across all age groups	0.719

				brought it to me”	**4.68 0.03**	**2.84 0.59**	
Other things, miscellaneous	7	17.9	13.7	“A nurse put tubes into my nose and mouth and she didn't label the nose tubes so the nurse had to do it again” “They come in to take my blood pressure all the time”	Girls=Boys **1.73 0.19**	Equal across all age groups **2.33 0.68**	0.642
Painful experiences	4	10.3	7.8	“Took longer than expected for pain medication” “When my nurse takes the tape off my body, it was painful because I am hairy”	Girls=Boys **0.39 0.54**	Equal across all age groups **3.69 0.45**	0.679
Not nice or friendly	2	5.1	3.9	“Makes fun of me” “One nurse was kind of mean (night nurse), made me roll over on my side when my back was hurting”	Girls=Boys **1.18 0.28**	Equal across all age groups **2.52 0.64**	0.456
Doesn’t talk or listen	1	2.6	1.9	“They ask what I need, after I minute they ask me the same thing again”	Girls=Boys **1.83 0.18**	Equal across all age groups **6.98 0.14**	0.697
No respect or privacy	1	2.6	1.9	“Having to follow the rules such as watching me take my medications and not leaving the room until I do”	Girls=Boys **1.83 0.18**	Equal across all age groups **3.98 0.41**	0.697

Table 4. Emotional Indicators on Human Figure Drawings by Hospitalized Children with Cancer

Emotional Indicator (EI)	Number of Children (n)	Percent (%) of Children
No nose	12	41.4
Shading body	10	34.5
No neck	9	31.0
No feet	8	27.6
Short arms	7	24.1
Hands cut off	7	24.1
Legs together	7	24.1
No arms	5	17.2
Tiny figure	4	13.8
Teeth	4	13.8
Big hands	4	13.8
No body	4	13.8
No legs	4	13.8
Asymmetry	3	10.3
Slanting figure	3	10.3
Long arms	3	10.3
Clinging arms	3	10.3
Monster	3	10.3
Big figure	2	6.9
Tiny head	2	6.9
Three figures	2	6.9
Shading hands	1	3.4
Transparency	1	3.4
Crossed eyes	1	3.4

No eyes	1	3.4
No mouth	1	3.4
Poor Integration	0	0.0
Shading face	0	0.0
Genitals	0	0.0
Clouds	0	0.0